DOCUMENT RESUME

ED 471 880 EC 309 331

AUTHOR	Hebbeler, Kathleen; Wagner, Mary
TITLE	The National Early Intervention Longitudinal Study (NEILS) Design Overview.
INSTITUTION	SRI International, Menlo Park, CA.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	1998-10-15
NOTE	15p.
CONTRACT	H159E950001
AVAILABLE FROM	For full text: http://www.sri.com/neils.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	EDRS Price MF01/PC01 Plus Postage.
DESCRIPTORS	At Risk Persons; *Data Collection; Delivery Systems; *Disabilities; Early Childhood Education; *Early Intervention; Educational Legislation; Family Characteristics; Federal Legislation; Infants; *Longitudinal Studies; Program Design; *Research Methodology; State Programs; Student Characteristics; Toddlers; Young Children
IDENTIFIERS	Individuals with Disabilities Educ Act Amend 1997; *Individuals with Disabilities Education Act Part C

ABSTRACT

The National Early Intervention Longitudinal Study (NEILS) is being conducted to address some of the most important questions related to the implementation and outcomes of Part C of the Individuals with Disabilities Education Act (IDEA). NEILS is following a nationally representative sample of children from birth to 3 years old and their families through and after their early intervention experiences. This report provides context and methodological background for interpreting the findings from NEILS. It describes the research questions, conceptual framework, sample, data collection instruments and procedures, and timeline for the study. (Author/SG)

Reproductions supplied by EDRS are the best that can be made
from the original document.

EC 309331

ED 471 880

SRI International

October 15, 1998

THE NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY (NEILS)
Design Overview

SRI Project 7879

Submitted to:

Scott Brown
Office of Special Education Programs
U.S. Department of Education
Switzer Building, Room 3522
330 C Street, S.W.
Washington, DC 20202-2641

Submitted by:

Kathleen Hebbeler
Mary Wagner

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

✓ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

NEILS is funded by the Office of Special Education Programs under cooperative agreement number H159E950001.

EC 309331

BEST COPY AVAILABLE

THE NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY (NEILS)

Design Overview

Before 1986, early intervention services were provided only in some states and only to some children with disabilities or developmental delays and their families in those states. The passage of Part H, now Part C, of the Individuals with Disabilities Education Act (IDEA), made the provision of early intervention services national policy. In the decade that followed the passage of the law, states built or adapted early intervention systems in accordance with their understanding of the law's vision. According to data reported to the U.S. Department of Education, the number of infants and toddlers served in early intervention program has grown steadily as state systems have developed (U.S. Department of Education, 1997). State evaluations and personal testimony have suggested some of the benefits and challenges associated with implementing this far-reaching legislation. However, much remains to be learned about Part C and the children and families who receive early intervention services under its auspices.

The National Early Intervention Longitudinal Study (NEILS), sponsored by the Office of Special Education Programs (OSEP), U.S. Department of Education, is being conducted to address some of the most important questions related to the implementation and outcomes of Part C. NEILS is following a nationally representative sample of children from birth to 3 years old and their families through and after their early intervention experiences. Current plans call for children and families to be followed from their entrance into early intervention until children are 7 years old.

To provide context and methodological background for interpreting the findings from NEILS, the following sections describe the research questions, conceptual framework, sample, data collection instruments and procedures, and timeline for the study.

Research Questions

NEILS is addressing four key study questions:

- Who are the children and families served through Part C?
- What early intervention services do participating children and families receive?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics and services received?

The study's approach to answering these questions is guided by a conceptual framework consisting of several related components (see Figure 1). This framework reflects a transactional/ ecological perspective, which holds that development in young children with disabilities is influenced by many interrelated factors, including those that are biological (e.g., genetic disorders), social (e.g., family members' interactions with the child), environmental (e.g., the toys available in the home), and cultural (e.g., the family's traditions and beliefs about child-rearing). Similarly, family systems theory views the family as a system that is influenced by many factors, including its composition, resources and supports available, the community in which it lives, and the family's beliefs and expectations. A critical feature of a transactional model is the assumption that there are reciprocal influences between the child and family. The family exerts significant influence over the child's development, but the child also influences the family through a need for care, the child's temperament, etc.

Components of the framework are described below.

Children and families. Describing the children and families in early intervention programs is one of the primary goals of the study. Understanding who they are is critical to understanding what happens to them during and after their early intervention experiences. The nature of children's abilities and disabilities will be a particularly important construct for nearly all of the NEILS analyses. The International Classification of Impairments, Disabilities, and Handicaps system (ICIDH; World Health Organization, 1980) will provide the framework for this description. Critical family variables include size, structure (parents married, divorced, never married, etc.), whether there is another child with a disability in the household, parental ages, race/ethnicity, languages spoken in the home, income level, receipt of public assistance, and the employment and education level of parents.

Children and families are intended to benefit from their participation in early intervention. Thus, documenting the outcomes experienced by children and families is another important goal of the study. Child outcomes measured in the study include:

- Developmental accomplishments in the domains of functional mobility; independence in feeding, dressing, and toileting; expressive and receptive communication; and object and social play.
- Functioning with regard to vision and hearing and the use of hands, arms, legs, and feet. These variables are both descriptive characteristics of the child and outcomes.
- Child engagement—how children interact with their environment, including distractibility, independence, activity level, and persistence.
- Child behavior. Behavioral aspects of infancy and toddlerhood include playing with other children, aggressiveness, temper tantrums, and difficulties related to sleep.
- Need for continued early intervention service.
- Progress toward outcomes specified in the Individualized Family Service Plan (IFSP).

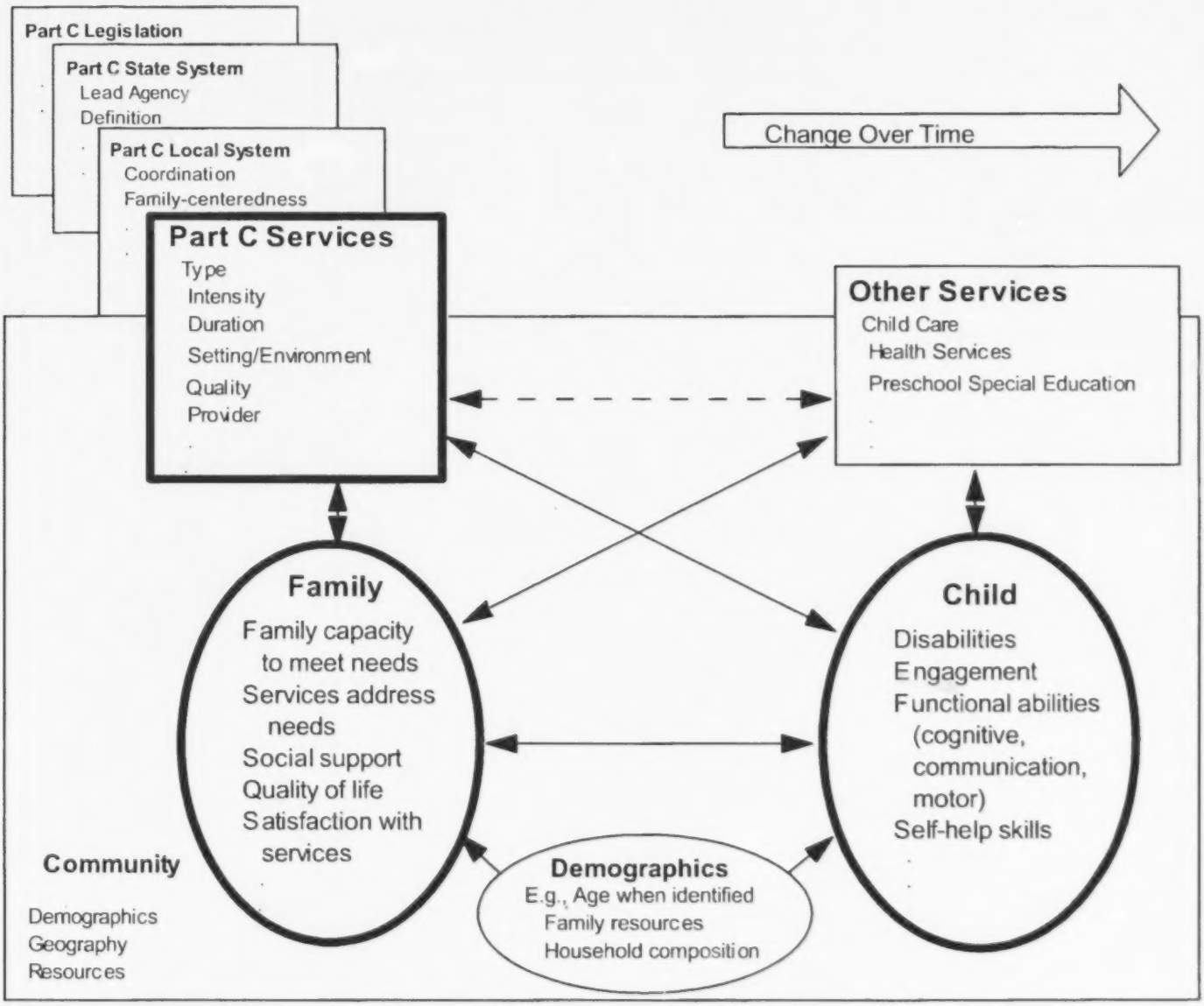

Figure 1 CONCEPTUAL FRAMEWORK FOR A LONGITUDINAL STUDY OF THE IMPACTS OF EARLY INTERVENTION SERVICES

3

- The extent to which parents report that early intervention makes a difference in the child's life.
- Parental reports of the child's quality of life.
- Need for special education.
- Academic achievement in early elementary school.

NEILS assesses two broad types of family outcomes. The first type of outcome refers to the family's perception of the early intervention experience, including:

- The services the child and family receive (e.g., service quantity and quality, degree of individualization, focus on the child's strengths vs. difficulties).
- Early intervention professionals who work with the child and family (e.g., the number of professionals and the communication among them, respect accorded the family, cultural competence).

The second type of family outcome refers to the perceived impact of the services on the family:

- The extent to which early intervention made a difference in the family's life.
- The extent to which early intervention enabled the family to help their child grow, learn, and develop.
- The family's ability to work with professionals and advocate for services.
- The family's support system.
- The family's view of the future.
- The family's quality of life.

Part C services. The framework depicts the services delivered to the child and family as one of the factors influencing outcomes for both children and families; indeed, this relationship reflects one of the major research questions for the study. Children and families are also hypothesized to exert influence on the nature of services they receive. Presumably, families and children with more intense needs would receive different kinds or amounts of service than those with fewer needs.

The dimensions of services being measured in the study encompass:

- Type of service (e.g., speech/language therapy).
- Location of service (e.g., home, center).
- Provider of the service (e.g., nurse, physical therapist).
- Quantity of service (e.g., minutes received in the past 6 months).
- Duration of service (e.g., number of months over which service was provided).

Other services. In addition to early intervention, the family receives other services that also are hypothesized to influence child and family outcomes. Health care and child care services are examples of such services that will be measured in NEILS.

Contextual factors. Part C and the local service system are shown as occurring in the context of multiple levels of implementation, including features of the federal law and regulations, the state-level translation of the law and other state contextual factors, and the local service delivery system.

The interactions between early intervention and other services and the child and family are embedded in and influenced by community-level factors, such as demographics (e.g., urbanicity), geography, and resources. For example, communities with high unemployment may have many families with limited financial resources who are experiencing high stress levels, which may result in less-than-optimum child development. These same communities may have few resources for services and thus may provide more limited or lower-quality early intervention services than communities with greater resources. This, too, would be hypothesized to produce less-than-optimum child development. Thus, community factors are seen as potentially affecting the child through the family and through the services provided.

Change over time. One final feature of the framework is its longitudinal nature. The study design recognizes that all the components change over time. Children's outcomes will change as they develop; multiple dimensions of family status also can change as children age and as families have more experience with early intervention. The nature of the early intervention services provided also is likely to change as children move from infancy through toddlerhood. Longer-term outcomes for children and families also are of interest. In addition to looking at the status of early intervention recipients over the course of program participation, the study will examine later outcomes for children and families, especially at the end of the preschool years and in early elementary school.

Sample

The study questions are being addressed with data collected about a nationally representative sample of children participating in early intervention for the first time and about their families. The sample has been designed to include approximately 3,800 children, to be drawn from 83 counties in 20 states.[1] Taking into account an assumed attrition of 10% per year, this initial

[1] As of November 10, 1998, the actual sample achieved is expected to be approximately 3,400 children. The sample size is lower than planned because several recruiting communities enrolled fewer children than expected during the enrollment period and more families than expected refused to participate in the study. When the shortfall was first predicted, the enrollment period was extended from 12 to 14.5 months to give recruiting communities more time to reach their enrollment targets. In addition, more counties were added to the sample in some states to compensate for sites that had particularly serious recruitment shortfalls.

sample size was determined to be sufficient to detect all but quite small differences in important variables when children reach their seventh birthdays. The NEILS sample design is described briefly below. More detailed information on the sample will be available in Javitz and Wagner (forthcoming).

State Sample

The state sample must maximize variations among states on important dimensions that influence early intervention. For example, selecting states that represent different geographic regions and population sizes will help ensure that the administrative challenges associated with state size and geography are represented. States also vary in the eligible populations they serve, particularly with regard to the inclusion of children designated as "at risk." Also, important program variations may flow from differences in states' designated lead agencies for Part C. A sample of 20 states was considered adequate to represent the variations desired.

An examination of the state-reported counts of children served on December 1, 1995, showed that the nine states serving the largest numbers of children under Part C accounted for approximately 60% of the participants in Part C nationally (U.S. Department of Education, 1997). These states were selected for the NEILS sample with certainty. To select the remaining states, the country was divided into three regions, and an additional 11 states were selected randomly from these regions with probability proportional to the size of the states' birth-to-age-3 population.

All states selected agreed to participate in the study.

NEILS Sample States

East	
Illinois	Michigan
Minnesota	Ohio
Massachusetts	New York
Pennsylvania	
South	
Arkansas	Florida
Maryland	North Carolina
South Carolina	Texas
West	
California	Colorado
Hawaii	Idaho
Kansas	New Mexico
South Dakota	

A target number of children to recruit for NEILS was assigned to each state by allocating the total sample to each region and then to each sampled state proportionate to the number of children served in Part C. The sample size for two less-populated states was increased further to ensure that a reasonable number of children were representing each state. The identified target sample sizes for individual states ranged from 46 to 389.

BEST COPY AVAILABLE

County Sample

The concept of "local community" for Part C services has many meanings because of the tremendous within-state variation in how early intervention services are organized and delivered. States are divided into local jurisdictions for the provision of services, but the nature and size of the jurisdictions differ from state to state. Because a uniform sampling unit was required across all states, the county was identified as the geographic unit for sampling. The county was identified as the local sampling unit because county boundaries are clear and many public agencies are organized around county lines.

Three to five counties initially were selected randomly for each state, the probability of selection being proportional to the size of the birth-to-age-3 population in the county, with the additional criterion that at least 10 children were projected to be served under Part C in a county. This latter provision was necessary for efficiency and cost-effectiveness in sample recruitment efforts.

A total of 83 counties initially were selected within the 20 states. Three of the originally selected counties declined to participate in the study and were replaced with previously identified alternates within the state. Eleven other counties were added late in the recruitment period when it became clear that some counties were recruiting families at a slower rate than predicted and that the total expected sample size might not be achieved.

Representing both urban and nonurban areas adequately was of particular analytic interest to the study. Using Census counts of children residing in rural and nonrural areas and U.S. Department of Education data on children served in Part C, we estimated that the sample would include 400 children from rural counties.

Each state's target sample was allocated to the counties to approximate the ideal of giving each child in Part C an equal probability of being selected. The size of the sample allocated to individual counties ranged from 4 to 134.

Child Sample

To recruit the sample of children, all "points of entry" in the sampled counties were contacted and asked to recruit families for the study. A point of entry (POE) is any program or agency by which a family could enter into the early intervention system in a county. Some counties have a single point of entry, whereas others have multiple locations where families can enter early intervention. Some counties with multiple points of entry are divided into smaller geographic units, with each unit having a single POE. Other counties have multiple entry points that cover the same geographic area but serve different types of children. A total of 193 POEs recruited children for the study.

The recruitment period for the study was September 1997 through November 1998. POEs in the sampled counties recruited for as long as necessary to reach their target numbers. The recruitment period for counties ranged from 2 to 15 months.

POEs were asked to provide a small amount of information on all families enrolling in early intervention during the site's recruitment period so that the study could describe briefly the full population of children and families that enrolled in early intervention, regardless of whether they participated in NEILS. However, lower-than-expected early intervention enrollment rates at some sites lead us to suspect that these sites may not have reported data on all enrolling families as they were instructed. Alternatively, shortfalls in enrollment may have resulted because projections were derived from state-reported enrollment data, which are known to be variable in definition and accuracy across states. In either case, NEILS data may not generalize to the entire population of children and families receiving early intervention, although the size of any discrepancy is unknown.

Programs were asked to invite into the study only families who had never received early intervention services for the target child. Among these families, only families who lived in the sample counties, whose child was less than 31 months of age, and who had either an English- or Spanish-speaking adult in the household were eligible for the study. If a family had more than one child eligible for early intervention (e.g., twins or triplets), only one child was eligible for the study. Overall, 85% of the families who were reported by points of entry as enrolling in early intervention during the recruitment period at their site were eligible for the study by these criteria.

As of October 1998, of families who were eligible to participate in NEILS, 69% have agreed to be in the study. Analyses will explore any significant differences between all families reported as enrolling in early intervention and those who consented to participate in NEILS. Statistical weighting procedures will take these factors into account in ensuring that the NEILS sample generalizes to all children and families *reported as enrolling* in early intervention.

The precise number of recruited children and families will be posted on the NEILS Web site in January 1999, when all recruitment information has been submitted by POEs (http://www.sri.com/policy/cehs/dispoly.html#neils).

Data Collection

Data are being gathered for the study at enrollment, as mentioned above, as well as from repeated family telephone interviews through children's third birthdays, from early intervention professionals who are knowledgeable about services provided to individual children and families, and through mailed surveys of other early intervention professionals serving NEILS families, and directors of programs or agencies that employ them.[2] Additional data collected from program directors will support an examination of expenditures on early intervention. Follow-up data collection also is planned when children are ages 5 and 7.

Enrollment Data

Information on a one-page form completed by the enrolling program on all families who enter early intervention for the first time reports the child's date of birth, race/ethnicity, gender, whether there is a phone in the home, whether the child is in foster care, whether the family receives public assistance, the nature of the condition or delay for which the child is eligible for early intervention, and the dates of referral and signing of the IFSP.

These data address important questions about the children and families enrolling in early intervention, such as the average age at which children with different apparent disabilities, delays, or risk factors are enrolled in early intervention, and some of the demographic characteristics of their families.

Additional information for families who agree to participate in the study include the name and location information of the adult who is best able to answer questions about the child and the name and location information of an early intervention professional who is best able to provide information about services provided to the child and family.

Family Interviews

Each family is interviewed by telephone shortly after agreeing to be in the study, at anniversaries of their enrollment until the child is 32 months of age, and at the child's third birthday. Interviews are conducted regardless of whether the child and family remain in early intervention. As mentioned above, follow-up interviews also are expected to be conducted when the child reaches ages 5 and 7.

Interviews are conducted with the family member identified as most knowledgeable about the child and the child's early intervention services. Families without telephones are sent a postcard

[2] No Program Director Survey is administered for early intervention professionals who are self-employed.

with the toll-free telephone number for the study and are encouraged to call and arrange an interview at a time and phone number that is convenient for them.[3] Computer-assisted telephone interviewing (CATI) guides the questioning sequence. Enrollment interviews last an average of 38 minutes. Interim interviews are marginally shorter, and interviews at third birthdays are slightly longer.

Questions in the enrollment interview ask about the circumstances of the child's birth and demographic information about the child and family. The enrollment interview also asks about the process of locating and entering early intervention. All interviews include items related to the child's development and behavior; health; and functioning with regard to vision, hearing, and mobility. As long as children remain in early intervention, interviews inquire about the early intervention services provided and perceptions of those services. Child care and preschool participation also are subjects of inquiry. When families are interviewed near the child's third birthday, they are asked additional questions regarding their overall perceptions of their early intervention experience, the type of assistance received in making the transition out of early intervention, and whether the child will be receiving any special services after early intervention.

Families who are not reached by telephone for an interview within a specified time period, are sent a 12-page mail questionnaire that contains key questions from the telephone interview.

Service Record

When a family enrolls in the study, the recruitment staff person at the POE identifies the early intervention professional who is the most knowledgeable about the services the family receives. At the end of each 6-month period after the first IFSP is completed, for as long as a child remains in early intervention, this identified professional is mailed a "Service Record," which collects information on the early intervention services for the child and family in the preceding 6 months. On the Service Record, the professional records the types of services provided in the preceding 6 months, the location in which each service was provided, the amount of service provided each week or month, and the kind of professional (e.g., speech therapist, nutritionist) who provided each service. The form also asks about the percentage of scheduled services the family missed in the preceding 6 months, the extent of the child's current delay or disability in each of nine areas (e.g., vision, hearing, gross motor development), and the child's progress toward the outcomes specified in the IFSP. If a child changes programs during a 6-month period, a provider from each program that served the child and family during the time period is sent a Service Record when each provider can be identified.

---

[3] If the adult respondent for the enrolled child is deaf, the telephone interview is conducted through a sign language interpreter whose services are arranged for by the early intervention program that serves the family and paid for by NEILS. One interview has been conducted in this way thus far.

When the child reaches his or her third birthday, a special version of the Service Record asks for the same information about services as the regular form but also asks what services the child and family are expected to need on leaving early intervention and whether the child will be receiving special education and related services through the local school system.

Service Provider Survey

The first Service Record sent to the early intervention professional who is most knowledgeable about services provided to a child and family also includes a form for the respondent to provide the names of all the other early intervention professionals who worked with the child or family during their first 6 months in early intervention. Each of these individuals is included in the NEILS Service Provider Survey. The mail questionnaire to early intervention professionals asks about the number and kinds of clients with whom the respondent works, the types of service s/he provides, the settings in which services are provided, perceptions of services in the area, and the respondent's background, training, and experience.

Program Director Survey

The Program Director Survey involves a sample made up of the director of each of the programs that employ an early intervention professional who serves a NEILS family in their first 6 months in early intervention[4]. The mail questionnaire asks about the number, types, and ages of the clients served by the program; the number and types of employed and contracted personnel involved in early intervention; the types of early intervention services provided; the settings in which services are provided by the program; the director's perceptions of early intervention services and coordination in the program's area; and the director's background training and experience.

NEILS Timeline

As mentioned previously, children and families enter the NEILS sample over a 14.5-month period, and much of the data collection is tied to when they enter the study. Thus, each stage of data collection extends over more than a year.

[4] The sample for the Program Director Survey is being developed from the list of early intervention professionals serving each family, which is described in the preceding section on the Service Provider Survey. This list is provided by the professional who is most knowledgeable about the services received by each family. There is no director in this sample for professionals who are self-employed.

- Family enrollment interviews will extend from November 1998 through February 1999. Interviews with families of children turning 3 years old will extend from March 1998 through February 2002. Family interviews for children turning 5 and 7 years old will be conducted from March 2000 through February 2004 and from March 2002 through February 2006, respectively.
- Mailing of Service Records began in March 1998. Data collection for Service Records covering the first 6 months of early intervention participation will be completed for the entire sample by summer 1999. Service Records will continue to be sent each 6 months as long as children remain in early intervention, which is likely to be through 2001.
- The Service Provider and Program Director Survey administration is scheduled for October 1998 through summer 1999.

Findings from NEILS will be reported as the various data collection components and waves are completed, with the first findings regarding characteristics of children and families who enroll in early intervention scheduled to be available in spring 1999. Results will be made available on the NEILS Web site as analyses are completed and reported.

REFERENCES

Javitz, H. and Wagner, M. (Forthcoming, 1999). *The National Early Intervention Longitudinal Study: Initial study sample*. Menlo Park, CA: SRI International.

U.S. Department of Education. (1997). *To assure the free appropriate public education of all children with disabilities. Nineteenth annual report to Congress on the implementation of The Individuals with Disabilities Education Act*. Washington, DC: U.S. Government Printing Office.

World Health Organization. (1980). *International classification of impairments, disabilities, and handicaps*. Geneva: Author.

NEILS is being conducted at SRI International under the leadership of Kathleen Hebbeler and Donna Spiker, co-principal investigators, and Mary Wagner, project director. SRI is conducting NEILS in partnership with staff of the Frank Porter Graham Child Development Center at the University of North Carolina-Chapel Hill (led by Don Bailey, Robin McWilliam, and Rune Simeonsson), the American Institutes for Research (led by Jay Chambers and Tom Parrish), and the Research Triangle Institute (led by Susan Kinsey and Haywood Allen).

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

NOTICE

Reproduction Basis

[ ] This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

[X] This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").